TESTIMONY
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Assessing September 11th Health Effects: What Should Be Done?

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Thank you for asking me to testify today. My name is Dr. Stephen Levin. I am the Medical Director of the Mount Sinai Center for Occupational and Environmental Medicine, the Director of the World Trade Center Medical Monitoring Program Data and Coordination Center, and the Co-Director of the Mount Sinai World Trade Center Health Effects Treatment Program. I am an Associate Professor in the Department of Community and Preventive Medicine in the Mount Sinai School of Medicine.

I have been asked to talk about the unmet health needs in the aftermath of the September 11 terrorist attacks on the World Trade Center. I hope that my comments can draw attention to the widespread and persistent health impacts of such disasters. There are thousands of men and women who are still ill and suffering as a result of their heroic rescue and recovery efforts after the World Trade Center was hit. The horrifying human suffering and loss of life caused by Hurricane Katrina has again shown the clear need for our nation to improve its planning and implementation of effective public health responses to man-made and natural disasters. A public health response should always include protecting the health of rescue and recovery workers as well as saving the lives and protecting disaster victims. In the heat of the effort to save the lives of victims, we have to minimize disability and illness among the rescue and recovery workers and those who bring such devastated areas back to life. Now, nearly four and a half years after the attacks on the World Trade Center, thousands of the men and women who worked in the rescue, recovery, and clean up efforts are still suffering. Respiratory illness, psychological distress, and financial worries have reshaped the lives many of these responders.

It's important to note that the WTC responders were provided with important medical programs that I'll talk about in just a moment. The many thousands of residents of lower Manhattan and the thousands of workers who returned to the area within days and weeks of 9/11 had no federally-funded services available to them to assess affects on their health. That's a public health need that remains unmet.

Medical Monitoring

In large part because of the efforts of New York's organized labor community and the clinical experience accumulated by Mount Sinai's Center for Occupational and Environmental Medicine and the Medical Department of the Fire Department of New York City, the federal government came to recognize that evaluating and monitoring the health consequences of the 9/11 attacks was important to the health of rescue and recovery workers. It was clear also that we had to learn all that we could about the health consequences of this horrific disaster. In June 2002, Mount Sinai received $11.8 million in federal funding to design a medical screening program and to organize and coordinate a consortium of health care centers in the New York metropolitan area and nationwide to provide free medical screening exams for WTC responders who were involved in rescue and recovery efforts, the removal of debris, the restoration of vital services, and clean-up of the surrounding buildings in the WTC area and Staten Island landfill. From its inception in April of 2002 to its end in August 2004, the clinical centers of the WTC Worker and Volunteer Screening Program provided a total of 11,794 examinations to a socio-economically diverse patient population; of those patients, 8838 were seen by Mount Sinai physicians.

In September 2004, we published in the CDC's Morbidity and Mortality Weekly Report some preliminary findings from an analysis of 1,138 of the first people to come through the program.

We found that:

- 60% of those examined had at least one WTC-related pulmonary (chest) symptom while working or volunteering at the WTC site, and 40% were still experiencing at least one pulmonary symptom in the month prior to the screening examination,
- 74% had had at least one WTC-related ear, nose or throat (ENT) symptom while performing WTC response work, and 50% were still experiencing at least one ENT symptom in the month of the screening examination,
- 43% reported mental health symptoms requiring further evaluation at the time of their screening examination, and
- 33% of patients had abnormal Pulmonary Function Test results. Among the 599 non-smokers, 31% had abnormal PFTS, as compared with only 13% that would be expected from studies of the general population in the U.S. (NHANES III). Thus, the rate of breathing test abnormalities in the WTC responders was 2-3 times background levels.

It's important to note that these persistent affects on health were still occuring on average 8 months after people had left the WTC site or activity and that these weren't just transient consequences. And what we are seeing in our clinical settings today - four years later - differs little from what we saw very early on in the program, and shortly we will provide data demonstrating the persistence of these physical and mental health effects among WTC responders.

Mount Sinai has received federal funding to serve as a Clinical Center and as a Data and Coordination Center for the World Trade Center Medical Monitoring Program, funded to provide follow-up examinations every year and a half for five years to responders who were seen in the Screening Program and to continue to provide first evaluations for World Trade Center responders who hadn't been able to be seen in the Screening Program. The WTC Medical Monitoring Program began seeing World Trade Center

responders in July 2004, and is presently conducting follow-up (Visit 2) examinations for World Trade Center responders as well as continuing to provide initial (Visit 1) examinations. As of February 1, 2006, the WTC Medical Monitoring Program at Mount Sinai has provided an additional 2475 initial (Visit 1) examinations and 3781 repeat (or Visit 2) examinations.

It's worth noting the number of people still coming to the program for an initial examination, more than four years after the attacks -- some because of concerns about persistent symptoms, some because they're worried about possible longer-term effects on their health. For many coming to our program, fears of future catastrophic diseases like cancer, which can take as long as twenty to thirty years to show up, loom as large or larger than their current illnesses. Because many WTC responders sustained unprecedented exposures of which the long-term consequences are unknown, this population should be under medical surveillance, with periodic medical examinations, for another thirty years – not primarily because we want to see what diseases they develop at higher rates as a group, even though this is important to learn – but especially to detect, as early as possible, diseases like cancer that develop years after exposure and that are much more effectively treated if we find them early. There are new approaches to early detection being developed in research labs across the United States and world-wide. It's important that we use the best tools we have to protect the health of this remarkable group of men and women, given what they've done. We estimate that current funding will permit the WTC Medical Monitoring Program to conduct examinations of 12,000

WTC responders once every year and a half for a total of five years only, lasting through 2009.

Treatment

One of the greatest concerns among the responders and those of us attempting to provide care to them is how and where they can receive proper treatment. While the federal government allocated funding for up to four screening and monitoring examinations, no federal money has thus far been provided to treat the WTC-related conditions found among the responders.

At Mount Sinai, we have sought and been fortunate enough to receive funding from private philanthropic sources to establish the World Trade Center Health Effects Treatment Program, designed to provide further testing and treatment for a limited number of WTC responders. As of January 30, 2006, the Health Effects Treatment Program has provided medical and social work services to almost 1900 World Trade Center responders.

Based on our accumulated clinical experience and what is known about the course of the illnesses found among our patients, thousands of World Trade Center responders have developed permanently disabling illnesses as a result of their exposures. Surprisingly, we continue to see new patients who have either never been treated for their WTC illnesses, or who have received less than the best of treatment, often from well-intentioned practitioners who have limited experience and training in evaluating and treating what were chemical burns of the airways. No government agency provided them with guidance regarding the nature of the WTC exposures, the expected health effects, or

approaches to their evaluation or treatment. We also know – based on over four years of clinical follow-up since the attacks - that thousands of World Trade Center responders will likely need long-term medical care for their World Trade Center-related physical and mental health conditions. To illustrate the basis for this concern, among 849 patients seen in the World Trade Center Health Effects Treatment Program, from August 1, 2005 to December 31, 2005:

1) 85% have persistent World Trade Center-related upper respiratory illnesses, such as chronic sinusitis.
2) 54% have persistent World Trade Center-related lung problems, asthma being the most common persistent World Trade Center pulmonary condition . Fully 37% of WTC responders in our treatment program are still being treated for asthma.
3) 72% have persistent World Trade Center-related gastrointestinal illness, the most common diagnosis being GERD or acid reflux, a condition known to worsen sinusitis and asthma.
4) 47% have persistent mental health consequences related to the World Trade Center disaster.

As many as on fourth of the population suffers from multiple WTC-related conditions: 26% of patients with asthma also had GERD; 21% of those with GERD also had chronic sinusitis; and among persons with an asthma diagnosis, 29% had concurrent diagnoses of both GERD and chronic sinusitis. This markedly increases the complexity of their treatment.

The data presented here are for patients seen in the treatment program roughly four years after they ended their exposures at the WTC site. The persistence and severity of their health conditions makes clear the need for ongoing treatment resources for these men and women. The WTC Medical Monitoring Program, like the WTC Worker and Volunteer Screening Program that preceded it, has identified a substantial number of people who need ongoing

treatment for World Trade Center-related physical and mental health problems. Unfortunately, there is still not an adequately funded treatment program for workers and volunteers who need ongoing medical care for their World Trade Center related health problems. Treatment resources received by our program are intended only as bridge funding and will run out in less than two years. At the current level of funding, there is a two- to three-month waiting period for new patients to be scheduled into our treatment program for a first visit with a doctor. And again, the funding we have received is intended only as a stop-gap measure until a more comprehensive and long-term source of support can be established.

It was important that programs were established with federal funds to evaluate WTC responders' health. But we are not doing all we should if all we can do is tell our patients, "You've developed asthma as a result of your WTC efforts; now go find treatment for yourself." Asthma medicines alone can cost several hundred dollars a month. The special breathing tests and CT scans our patients need can cost hundreds. Many (over 50% of our patients in Mount Sinai's treatment program) have no health insurance or are underinsured, with high deductibles and copayments. Many construction workers and others have lost their health insurance (and their family's coverage) because WTC-related illness has made it impossible to put in the required number of work hours required by their benefit plans. Many have found nothing but insults and frustration when trying to contend with a Workers' Compensation system in New York that adds additional stress and misery to their already considerable psychological burdens. A small proportion of claimants have had their cases accepted expeditiously for their WTC-related illnesses. The majority filed claims that were fought tooth and nail by Workers' Compensation

insurance companies or self-insured employers, with genuine heroes being accused of lying and malingering and their testing and treatment delayed for months and even years.

The fragmentation of health care delivery in the United States can be seen all too clearly in the challenges these heroes have had to face simply to get treatment for their WTC-related illnesses. Further, it's reasonable to project that philanthropic organizations will find their financial resources stretched even further in the future. The medical and psychosocial needs of the victims of and responders to disasters like Hurricane Katrina provide evidence of this. WTC-responders should not have to go hat in hand to philanthropic sources for help. They are ill because our country was attacked and because they responded in an effort to help. Their care should be a governmental responsibility. Furthermore, it is urgent that funding be made available to provide access to medical and mental health care for all who sustained health consequences from the World Trade Center disaster - workers and volunteers involved in rescue recovery efforts, workers who returned to their jobs in the immediate WTC area, and area residents and their children. This would be responsible public health policy and would reflect a comprehensive public health approach. No publicly funded program now exists to provide care to residents, including children, with WTC-related health problems, nor to workers from the area surrounding the WTC disaster area who may have developed health effects but were not involved directly in rescue and recovery efforts. Federal responders are another group that has been left out of the government's programs, although there is currently discussion about how to provide evaluations for them. Funding is critically needed to:

1) Supplement the current appropriation of $90 million in order to extend the duration of the long-term medical monitoring program for responders for an additional 20 to 30 years;
2) Ensure access to all diagnostic testing necessary to confirm or rule out possible WTC-related health problems identified among responders in the screening examinations and to provide treatment for all of their WTC-related health problems;
3) Ensure that those responders who develop future health problems related to their WTC exposures are able to receive treatment for those conditions;
4) Support clinical research to better understand the human health consequences of World Trade Center exposures and identify treatment modalities for those conditions; and
5) Develop clinical programs for the assessment and provision of care for WTC-related health effects among WTC area workers and residents.

Much of the suffering we are seeing among World Trade Center responders could have been prevented or been made less severe had adequate information about the potential health effects of WTC exposures been disseminated promptly, had appropriate protective measures been rapidly made available to and used by responders in order to prevent those exposures, and if early diagnosis and treatment of WTC-related health problems had been more readily available. Local and federal agencies need to work together with occupational health experts and others to establish a critically needed infrastructure to monitor and provide treatment for the health effects of this attack, and to be prepared in the event of future disasters.

Unfortunately, we know that it is possible that future terrorist attacks or natural disasters will occur in the United States. We must ensure that there will be an adequate public health infrastructure in place and a rapid flow of funding to permit prompt assessment of exposures and their clinical consequences, as well as dissemination of information about how to prevent potential health effects of those exposures to the affected communities. It is also vital to provide information to treating physicians and to develop programs to

provide early diagnosis and treatment. Surely, heroes deserve no less, and the people who live in this, the wealthiest of nations, have reason to expect that in the face of disaster, their health needs will be our country's priority.

Thank you.